DOCUMENT RESUME

ED 309 907 RC 017 193

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TITLE An Introduction to RTC: Rural /The Research and Training Center on Rural Rehabilitation Services.
PUB DATE Jul 88
NOTE 18p.; Paper presented at the Annual National Institute on Social Work and Human Services in Rural Areas (13th, Fort Collins, CO, July 24-27, 1988).
PUB TYPE Speeches/Conference Papers (150) -- Reports - Descriptive (141)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Accessibility (for Disabled); Adjustment (to Environment); *Disabilities; Rehabilitation; Rehabilitation Centers; *Rehabilitation Programs; *Rural Areas; *Rural Education; *Rural Urban Differences
IDENTIFIERS University of Montana

ABSTRACT

It is estimated that nearly 8.5 million people living in rural America possess some form of disabling condition. Strokes are the major cause of disabilities among older persons and accidents are the major cause among teenagers and young adults. This paper provides background information on rehabilitation services in rural areas, some examples of the special problems faced by disabled persons living in rural areas, and a description of a national center, the Research and Training Center on Rural Rehabilitation Services, established at the University of Montana in October 1987. (Author)

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AN INTRODUCTION TO RTC: RURAL /THE RESEARCH AND TRAINING CENTER ON RURAL REHABILITATION SERVICES

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Paper presented at the 13th Annual National Institute on Social Work and Human Services in Rural Areas
July 24-27, 1988
Fort Collins, Colorado

RC 017193

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INTRODUCTION:

The primary purpose of our presentation is to make you aware of a new national center for rural rehabilitation research and training which has been established at the University of Montana.

Our presentation will provide some background information on rehabilitation services in rural areas, some examples of the special problems faced by disabled persons living in rural areas and a description of the new national center officially known as the Research and Training Center on Rural Rehabilitation Services. For purposes here we will refer to the center as simply the RTC.

As a way of introducing the RTC and its goals, we will begin with a brief review of certain aspects of rural life that relate rather directly to the special problems of providing rehabilitation services in rural areas.

THE DISABLED PERSON IN RURAL AMERICA:

It is estimated that nearly 8.5 million people living in rural America possess some form of disabling condition. In general, it can be said that strokes are the major cause of disabilities and accidents are the major cause among teenagers and young adults. When compared to their urban counterparts, the

disabled living in rural areas tend to be older, less well educated and have lower incomes. Needless to say, those of us that have a special interest in social work practice in rural areas are troubled by the fact that this population of disabled persons has so many unmet needs and are inadequately served by existing programs. For example, North Dakota has a population of about 650,000. Each year in that state about 3,000 individuals have a stroke. About 1 in 4 will die. Thus, each year there are about 2,200 that survive their first stroke. All are left with some degree of disability. Yet of those 2,200 only about 200 receive services from the states only rehabilitation center in Grand Forks. So about 2,000 who need rehabilitation services do not receive them.

Whenever one attempts to discuss problems of the disabled, it is well to remember the distinction between the terms "disabled" and "handicapped". That distinction is helpful in understanding some of the special concerns of disabled persons living in rural areas. All persons with a handicap are disabled but the persons that are disabled are not necessarily handicapped.

Eventually, a disability is a permanent or at least long lasting condition that limits normal physical or mental functioning. We consider an individual handicapped when they are unable to perform an important life activity or carry out a key social role such as the work role because of a disability.

For the purpose of gainful employment, loss of the

> ability to walk [a disability] might handicap a construction worker but not an accountant. Likewise, such a disability might not handicap an office worker in a city with wheelchair access to good public transportation, but it might be handicapping to the same worker in a city with poor [or no] public transportation and no provision for wheelchair access. However we define disability, it should be clear that the population does not divide neatly into disabled and nondisabled person. (Mathematica Policy Research, 1984, p.xiv)

In other words, whether or not a physical or mental limitation is a handicapping condition, depends - to a large degree - upon the person's environmental context and other personal characteristics such as their expectations, roles motivation and values. Such a notion is of course familiar to social workers who utilize the ecological perspective in their practice (see for example Germain and Gitterman, 1987) and were taught in their very first social work course that the objective of the social work profession was to bring about person-environment transactions that promote growth, health and social functioning and also to improve the environments in which people must function.

Certain characteristics of the rural environment not only increase the incidence of disabling conditions but also increase

the likelihood that the condition will prove to be a significant handicap for the individual. This is most clear when we consider that farming, logging and mining - all common occupations in rural areas - are hazardous occupations.

Also consider the fact that rural people drive long distances - often on poor roads and during bad weather. Many disabilities result from car accidents. The high accident rate is also related to the heavy alcohol consumption common in many rural areas.

An individual who becomes disabled must often change occupations and seek employment that does not require physical strength and a full range of movement. The problem is that there are few such jobs in rural areas. Most employment in rural areas center around physical activity. Thus the person who is disabled person and living in a rural area has fewer opportunities to find meaningful employment. To find a suitable job they may need to move to an urban area and this means the rupture of relationships with supportive friends and relatives and the loss of the belongingness and acceptance they feel in a small community.

And of course, there are the problems associated with a changing self image and body image. In a rural area so many social and recreational activities involve physical strength and skill. For example, in a typical small town in Montana many family and community activities center around soft ball, hunting, fishing,

and other active outdoor sports. The inability to participate in those activities can be especially painful because they are so much a part of the community fabric and there are few alternatives.

Rural communities lag behind urban areas in making public buildings accessible to the handicapped. Gravel streets without a sidewalk are still common in rural towns. A wheelchair is tough to move on gravel or in mud.

Characteristics of rural life also complicates the provision and delivery of rehabilitation services. Rehabilitation services, like other forms of specialized health care, are few and far between in rural areas. A stay in a rehabilitation center can easily last from several months. The patients' family must travel long distances in order to keep in touch with their disabled family member and participate in meetings with rehabilitation professionals. Also, such services are very expensive. Of course they are also expensive in urban areas but the typical rural family is even less able to pay. For one thing, the income of rural residents are from 20-40% lower than for urban residents. Moreover, people in rural areas are less likely to have health insurance. The inability to secure payment for services places a special burden on the rehabilitation centers that do serve the rural population.

When the disabled person leaves the hospital or rehabilitation

center and returns to his or her home community they face the problem we know so well - the lack of adequate resources in rural communities. Often local doctors and other health care personnel do not understand or have had very limited experience with the many medical complications associated with severe physical disability. Similarly, other local providers of human services may be poorly prepared to assess and respond to the special needs and often subtle problems of the disabled, especially the disabled that have experienced brain injury. Also we have become aware that a great many human service professionals, including social workers and psychologists, have little awareness of the special services that can be provided by physical therapists, occupational therapists and speech therapists. Many have never heard of a physiatrist or if they heard the word they believed the speaker meant to say "psychiatrist". (A physiatrist is a physician specializing in rehabilitation medicine). If other human service professionals are not aware of the various multidisciplinary rehabilitation services and how they might benefit the disabled person and his or her family, they cannot make appropriate and timely referrals.

All too often the rural family is left to struggle alone in their attempt to care for a disabled family member. Even with appropriate services this can be very stressful. Without supportive services it becomes overwhelming. Often the severe stress destroys the families ability to function and eventually a

crisis precipitates a nursing home placement.

We often see a special form of family frustration that occurs when the disabled person leaves the rehabilitation center and returns to live with his or her family in a small community. During the patients stay in the rehabilitation center the family learns about the various members on the multidisciplinary rehabilitation team - physiatrist, PT's, OT's, social worker, speech therapist, psychologist, recreational therapist, nurse, nutritionist, etc. - and the family comes to appreciate the services they can provide. But once they are back in their home community, they discover that these professionals do not exist in their communities. They discover that the local doctor - if there is one at all - does not know much about the problems of disabled people. There may be a speech therapist in town but she only works with school children. Neither the psychologist nor the social worker at the nearest mental health center - both of whom are trained to provide "talk therapy" - have much to offer the disabled person who has trouble speaking and cannot process verbal information. So the family experiences a great deal of frustration. They are well aware that their disabled family member needs services, but the needed services are simply unavailable in their home community.

Other special programs such as supportive employment, case management, and independent living are also lacking in rural and isolated areas. Even the relatively simple, inexpensive and

effective programs of self help are lacking in most small rural communities - usually because of the small number of persons in the area with the same disabling condition. There are not enough individuals to form a support group. Even when a self help group does exist, many rural residents are reluctant to participate because they do not want to talk about their concerns in the presence of friends and neighbors. As you know, gossip and a lack of privacy can be a real problem in rural communities.

HISTORY OF RURAL REHABILITATION:

It is important to realize that the concept of rural rehabilitation did not emerge until the early 1980's. It is also noteworthy that much of the work of conceptualizing rural rehabilitation took place in our nearby state of North Dakota.

In 1978, The Rehabilitation Administration Services released a film entitled "Too Few, Too Far to Matter" which depicted problems in delivering rural health services in Montana, New Mexico, and South Dakota. What it clearly showed was the bias in policy making, program development, and fund distribution towards urban areas and the expectation that models of rehabilitation developed in urban areas could be simply transplanted in rural areas. Historically, the majority of rehabilitation facilities and programs have been located in metropolitan areas and associated with major institutions of higher learning. But what works in the big city may not work in the rural area.

It was not until 1982 that a study (Rural Rehabilitation: A State of the Art, Leland and Schneider) focused attention on the limited literature dealing with rural rehabilitation. Only 80 relevant documents were identified.

Close on the heels of this study was a second (also published by the Arkansas Research and Training Center) entitled Disability in Rural America: A Four-county Needs Assessment (Omohundro, J; et al: 1983). Surveying the needs of 456 disabled individuals in Texas, Oklahoma, and Arkansas, this study concerned itself with the unique rehabilitation needs of Blacks, Indians, Mexican Americans, and Ozark Whites.

These two early works provide valuable reference points for the state of thinking concerning rural rehabilitation in this country and seemed to stimulate interest in the topic. A case in point is a literature search conducted by the National Rehabilitation Information Center (NARIC) in the fall of 1987 which yielded over 240 articles dealing with some aspect of rural rehabilitation. This is a three-fold increase over the 80 articles in 1982 and represents an encouraging sign in increased awareness and energy in rural rehabilitation research.

Two very successful events brought together hundreds of rural rehabilitation-oriented providers and consumers at the University of North Dakota in 1984 and 1985: the 1st and 2nd International Conferences on Rural Rehabilitation Technologies (ICRRT). A

rural rehabilitation technology data base was also developed by the same group at UND in 1986. The former have added considerable to the literature on rural rehabilitation, while the latter has become part of the growing collection of publications being made available to both consumers and providers in rural areas.

Along with these efforts, extensive work has taken place within the U.S. Congress in terms of a growing recognition of the special needs of the rural disabled. Numerous model projects are under way across the country, including such innovative efforts as the work by Bill Fields, editor of Breaking New Ground (Purdue University, IN), and the CARES Project (Medical Center Rehabilitation Hospital, Grand Forks, ND). Through such efforts we are beginning to see what needs to be done and can be done for disabled farmers, disabled children and the disabled elderly who live in rural America. Special projects are underway through the support of the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education to explore the special needs of persons attempting to live independently in rural settings, adapt agricultural equipment, utilize technology, and address the specific needs of disabled Native Americans, as well as other related concerns.

THE RTC:

The establishment of the Research and Training Center on Rural Rehabilitation Services (RTC:Rural), at the University of Montana, signals a commitment on the part of the Federal government to formally and finally address the needs of the rural disabled.

Needless to say, the new Rural RTC - or a hundred like it - can never solve the many problems inherent in providing services in rural and isolated areas. But, it will attempt to focus greater attention on the needs of the disabled living in rural areas and will launch a number of research and training efforts designed to obtain a better understanding of problems related to the delivery of rehabilitation services in rural areas.

The Research and Training Center on Rural Rehabilitation Services (RTC:Rural) was established at the University of Montana in October, 1987, with funds from the U.S. Department of Educations's National Institute on Disability and Rehabilitation Research (NIDRR). The Center has been funded for five years but is expected to continue beyond 1992.

The RTC:Rural is one of 35 centers nationally that are funded by the NIDRR to conduct research and training related to the disabled. However, the RTC at the University of Montana is the only one of these 35 centers whose specific focus is on the needs

of disabled persons living in rural areas.

The RTC:Rural will focus on the following research and training areas:

1. Adapted and modified devices and technology
2. Rural services delivery practices
3. Telecommunications technology and information systems
4. Training and information dissemination

More specifically, RTC objectives are as follows:

Objective 1:

Develop methods to adapt or modify technological devices for disabled persons to accommodate the particular circumstances of rural areas.

Objective 2:

Evaluate and document technological adaptations and develop a database that can be used to provide information about the availability of modified devices and funding sources for these adaptations.

Objective 3:

Conduct programmatic research on the characteristics and needs of residents with disabilities, identify the most effective strategies to improve the daily lives and enhance the independence of these individuals, and identify the most effective approaches to the delivery of rehabilitation services and information services in rural areas.

Objective 4:

Conduct research on the innovating application of telecommunications technology to problems of health care, rehabilitation, service delivery, and independent living for disabled individuals in rural areas.

Objective 5:

Develop an information system that is accessible through telecommunications devices and that includes the database on adapted technology, as well as other information on resources to assist rural disabled individuals to improve their housing, employment, transportation, attendant care, communications, recreation, or physical function.

Objective 6:

Develop and disseminate accessible materials and training programs targeted to disabled persons and service providers in rural areas, including the staff of independent living programs, in order to increase consumer awareness and professional expertise.

Objective 7:

Develop cooperative linkages to relevant NIDRR-supported research programs in technology transfer, independent living, and service delivery to dispersed populations.

Objective 8:

Conduct at least one state-of-the-art conference in a significant aspect of rural rehabilitation service delivery, and develop a nationally recognized expertise in the delivery of rehabilitation services and dissemination of rehabilitation information to rural areas.

In addition to its central office at the University of Montana, the RTC is affiliated with the Rehabilitation Center at Missoula's Community Medical Center. RTC's "Rehabilitation Engineering Unit" has been located in the Department of Mechanical Engineering at Montana State University in Bozeman.

The RTC is publishing a news letter titled The Rural Exchange. The Director of the RTC is Dr. Richard Offner. If you desire additional information call or write

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